Governance Workgroup
Draft Transcript
September 3, 2010

Presentation

Judy Sparrow – Office of the National Coordinator – Executive Director
Good afternoon, everybody, and welcome to the governance workgroup. This is a workgroup of the HIT Policy Committee, which is a FACA committee, and at the end of this call, there will be opportunity for the public to make comment. Let me do a quick roll call of the workgroup members, and also remind the members to identify yourselves when speaking. John Lumpkin?

John Lumpkin – Robert Wood Johnson Foundation – SVP & Director
I'm here.

Judy Sparrow – Office of the National Coordinator – Executive Director
John Glaser?

John Glaser – Partners HealthCare System – VP & CIO
Here.

Judy Sparrow – Office of the National Coordinator – Executive Director
Laura Adams?

Laura Adams – Rhode Island Quality Institute – President & CEO
Here.

Judy Sparrow – Office of the National Coordinator – Executive Director
Leslie Harris?

Leslie Harris – Center for Democracy & Technology – President & CEO
Here.

Judy Sparrow – Office of the National Coordinator – Executive Director
Christine Bechtel? Neil Calman?

Neil Calman – Institute for Family Health – President & Cofounder
Here.

Judy Sparrow – Office of the National Coordinator – Executive Director
John Mattison? Girish Kumar?

Girish Kumar – eClinicalWorks – CO
Yes. Here.

Judy Sparrow – Office of the National Coordinator – Executive Director
Linda Fischetti? Michael Matthews?

Michael Matthews – MedVirginia – CEO
Here.

Judy Sparrow – Office of the National Coordinator – Executive Director
John Houston?

John Houston – Univ. Pittsburgh Medical Center – VP, Privacy & Info Security
Here.

Judy Sparrow – Office of the National Coordinator – Executive Director
Carol Diamond?

Carol Diamond – Markle Foundation – Managing Director Healthcare Program
Here.

Judy Sparrow – Office of the National Coordinator – Executive Director
Wes Rishel? Tim O'Reilly? Mary Jo Deering?

Mary Jo Deering – ONC – Senior Policy Advisor
Present.

Judy Sparrow – Office of the National Coordinator – Executive Director
Joy Pritts, you are on? Mariann Yeager?

Mariann Yeager – NHIN – Policy and Governance Lead
I'm here.

Judy Sparrow – Office of the National Coordinator – Executive Director
Elliott Maxwell and Steve Posnack? Did I leave anybody off?

W
May I ask, is Farzad Mostashari on the phone? Okay.

John Mattison – Kaiser Permanente – Chief Medical Information Officer
This is John Mattison.

Judy Sparrow – Office of the National Coordinator – Executive Director
Good morning and good afternoon, and I'll turn it over to John Lumpkin.

John Lumpkin – Robert Wood Johnson Foundation – SVP & Director
Good afternoon. For those on the West Coast, still good morning, and thank you all for participating. This is our first full meeting call, and as you can see on the next slide, the purpose of this call is to do a couple things. We're going to talk a little bit about the activities of the workgroup, what our focus will be. We'll talk a little bit about the scope of NHIN's governance. But most of the time we're going to focus in on the two work paths and that is identifying those and working on the panels for September 28th and confirming the process for drafting the recommendations.

Next slide: So our agenda today is to go over a little bit of the background, as I mentioned the charge, scope, and focus, and then how we're going to accomplish our tasks. So let's go into the background.

Next slide: As all of you are, I'm sure, aware that HITECH directed the national coordinator to establish a governance mechanism for the National Health Information Network. For those of you looking at the slide recognize that that name is in the process of being changed. Some of us old timers are thinking the National Health Information Infrastructure was kind of a neat name, but whatever new name we will use, the entity itself will not change. This activity, as directed by HITECH, would be to develop a rulemaking, and so it is the intent of ONC to … our efforts to develop an NPR, a notice of proposal … that deals with issues of governance related to trust, assuring effectiveness of the information exchange network that will meet and exceed consumer expectations, particularly related to privacy and security, and promote and facilitate the use of the National Health Information Network.

Next slide: The question some may be asking, like me when I was first asked to do this, is why are we doing this now. The short ….

W
You're breaking up on this end.

John Lumpkin – Robert Wood Johnson Foundation – SVP & Director
Am I back?

W
I don't think I'm the only person having this problem.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst
No.

M
No.

John Lumpkin – Robert Wood Johnson Foundation – SVP & Director
I think you can sort of follow … is my signal a little bit better now?

W
Not really.

John Lumpkin – Robert Wood Johnson Foundation – SVP & Director
If not, it's all AT&T's fault. Let me go on. The governance is essential to make decisions needed to accomplish HIT agenda and the HITECH goals. It's necessary for existing limited production of exchange, and in order to validate and assure the conditions for truest nationwide … exist. Now we know at this particular point a number of states are already starting to establish some governance roles. In our workgroup handout, there were materials from Minnesota, I believe—or was it Michigan—Minnesota, where they've already begun to establish state regulations on this. So if we're going to have a system that is transparent in its oversight, transparent and effective in its enforcement, and assures that all parties are accountable so that trust can occur, governance becomes a critical issue. That's the rationale for why we're looking to go into governance now, and so the next issue then is what is our charge for the workgroup. Let me just pause here and see if there are any questions about why governance now.

Next slide: The charge is to draft a set of recommendations on the scope and process of governance for a Nationwide Health Information Exchange including measures to insure accountability and oversight. Now that's kind of a broad mechanism. And, as you see a little bit later in a couple of slides, we're going to talk a little bit about how we're going to try to cone that down to particularly focus in on those aspects related to the roles of the Office of the National Coordinator and those areas of governance that are so critical that we would expect that ONC would have some comment related to it.

The related purposes of this workgroup is to provide recommendations to engender trust in the National Health Information Exchange Network, and this means that in order for this thing to work, for individuals who participate in exchange, both either as having their information be moving through the network or their providers giving their information, there needs to be a level of trust … that their information will be handled as carefully by another exchange as it is the exchange in which they participate. The second related purpose is to facilitate development of a notice of proposed rulemaking, the NPRM that I mentioned before. And then our third task related purpose will be to provide comment on the NPRM when it's issued. So that means after we accomplish our initial phase of work that we will be … waiting for the NPRM to come out, and then … commenting … 2011.

Next slide—

M
Excuse me. It sounds like there's some background noise. Can we make sure everybody puts their phones on mute?

John Lumpkin – Robert Wood Johnson Foundation – SVP & Director
Our specific deliverables—and I would like everyone to focus in on that—is that we're going to be having a hearing on September 28th where we hope to get an idea from the field itself how they look at these issues. We are slated in a very short timeframe to have additional recommendations to the HIT Policy Committee by October 20th and financial recommendations by November 19th. Then we would expect that we would have some hearings and comments on the NPRM when it's issued later in 2011. That obviously is a fairly tight timeframe, and when we get to the last part of our agenda, we'll have some discussion about how we're going to focus in on accomplishing this task. Any questions about our deliverables and timeframes?

Michael Matthews – MedVirginia – CEO
Is the hearing sponsored by their workgroup, or is it by the overall committee?

John Lumpkin – Robert Wood Johnson Foundation – SVP & Director
Mary Jo and the rest can correct me, but I believe this is our workgroup's sponsored hearing. Any other questions?

Moving on, so let's talk a little bit about the scope and focus of this. First of all, we're going to start off with the definition, and this is one that I'm sure all of you have seen before defining what the National Health Information Network—that term that will be changing—is. Of course, it's important to note, because we always do this, it's not a centralized database, and then includes a set of core functionality. And it's not inclusive of all health information exchange that will occur. So when we think about exchange, we're going to be looking at the framework that's within the context of what we now call the NHIN.

Next slide: So our guidance is to, what we want to do is to recognize and leverage existing governance mechanisms where feasible. That was the purpose for the materials that were sent out to the workgroup to get us a good feel for the work that had been done before. We don't want to recreate the wheel where it exists, but we want to identify gaps in the existing governance mechanisms, and our path will be to make recommendations that would bridge those gaps. We want to identify those aspects of governance, both existing and new where coordination would enhance or promote greater trust, and particularly with the interest that what we want to do is facilitate exchange in a meaningful and safe way that will enable better operation of the healthcare system. We want to promote the broad utilization of core functionality, including the standard services and policies for the National Health Information Network.

Next slide: So the governance mechanisms for the network could do some of the following things, and I think these are just examples, and what we're going to do is have to flush these out. It would be a preferred option for trusted and interoperable health information exchange where levers could be … encourage its use so that people who voluntarily participate in networks will be subject to the governance and applicable law. And recognizing that those who do not participate would not be exempt from applicable law, but would be able to exchange data outside of the system. It's obviously that we would be able to control. It would also establish a process for assuring use of identified standards and services that promote interoperability within the network. So part of this is talking about the process of defining the policies that promote and facilitate health information exchange through this network, and that a key component of that is protecting privacy and security.

Leslie Harris – Center for Democracy & Technology – President & CEO
You just hit a … finding … I don't know if you said defining or identifying the policies, but my understanding is we are not a policy group. There are all kinds of policy.

John Lumpkin – Robert Wood Johnson Foundation – SVP & Director
Right, and that's the reason why I said there may be certain policies related to governance that we want to talk about, but most of that is defining the process of how those policies will be put in place. Basically who does it, and who does it affect?

Leslie Harris – Center for Democracy & Technology – President & CEO
I'm trying to get my brain around this. It's not going to be a compliance body for law. I assume that's the responsibility of …. So are we talking about proposed policies that come out of the policy committee? We say it's ONC specific. Is that what we're talking about?

John Lumpkin – Robert Wood Johnson Foundation – SVP & Director
(Inaudible.)

Leslie Harris – Center for Democracy & Technology – President & CEO
…the whole list of private, that's been coming out of the policy committee? I got a little confused about the line between the legal mandates and policies, which might be enforceable by contract, but right now probably are not otherwise.

John Lumpkin – Robert Wood Johnson Foundation – SVP & Director
So why don't you hold that for a second, and if I don't answer it within like the next slide or two, let's come back to that. Okay?

The last point on this slide is that also a process for providing oversight enforcement and accountability, so if we're going to have a system that's built upon trust, there has to be a process to make sure that people are in fact engaging in those trustworthy activities to protect privacy and security that are holding this information that's being exchanged in trust. There has to be accountability of those elements, whether they be individual health information service providers or exchanges.

Next slide: I hope this one will help answer, so our focus will be on determining the process and structures to insure trusted health information exchange. It is not our focus to determine the specific standard services or policies. That will be other committees and ONC's job to do. We will be focusing on examining aspects of government within ONC's authority or control.

For instance, establishing a preferred option for how health information is exchanged. We won't be engaged in examining aspects of governance outside of ONC's authority or control unless it's a critical dependency. So as we're going through this process, we'll just have to think that we pretty much want to keep within that sphere unless we believe there's an overarching, overwhelming reason that ONC needs to pay attention to those other aspects of governance.

Then, finally, we need to identify any mandatory and optional requirements for the preferred approach for health information exchange. So we're essentially talking about developing a network, which is a preferred method, and we're not going to be looking at those requirements for those who elect to exchange information in another way.

Next slide—

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst
John, I missed the first three minutes of the call or the three minutes of your presentation, and I'm hearing the usual forming kinds of issues around getting a new committee focused on its work. Historically, I believe this committee arose because it was determined that the NHIN couldn't go to broader membership absent a regulation. To a certain extent, is it reasonable to characterize our work is determining the degree to which the current DURSA is suitable as opposed to starting from the ground up, figuring out the answers to these questions?

John Lumpkin – Robert Wood Johnson Foundation – SVP & Director
Sort of. I think, first of all, I don't think we should operate on the assumption that the current DURSA is it. And I say that because the current DURSA, which is, as I read through it, I think, hits a lot of the issues. But we've learned a fair bit since that was first implemented on what are the governance issues related to exchanges, sharing information with each other. So the answer is yes, but—

The second component of your answer is yes. These regulations really have to deal with how people can participate in a National Health Information Network, whereas it will be called whatever else it will be called, without it being a federal contractor or grantee.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst
Right.

Carol Diamond – Markle Foundation – Managing Director Healthcare Program
The other distinction I want to be sure that we keep in our terminology is that the DURSA is not a governance mechanism. The DURSA is a means of contractural enforcement of policies and standards and other things necessary for information exchange. And it's one mechanism of enforcement, but the question of governance is larger, both in the aspect of policymaking, and also in the abstract of policy enforcement and oversight.

John Lumpkin – Robert Wood Johnson Foundation – SVP & Director
Yes.

Joy Pritts – ONC – Chief Privacy Officer
I think that where this conversation has ended up is exactly where we need it to be, which is that we don't want to start from scratch because there's been a lot of work on some existing material. Yet we also recognize that although looking at that work may be necessary, it is not sufficient.

John Lumpkin – Robert Wood Johnson Foundation – SVP & Director
I'm going to pause here. We have a couple of … questions, but I think where we're at right now is really focusing in on what it is that we're trying to accomplish, so I want to see if there are any other questions ….

Linda Fischetti – VHA – Chief Health Informatics Officer
This is Linda Fischetti just letting you know that I have joined.

Doug Fridsma – ONC
This is Doug Fridsma, also just joined.

John Lumpkin – Robert Wood Johnson Foundation – SVP & Director
What are the key questions? I think that the first and foremost is what needs to be governance … HIE level. There are certainly … issues that rise at the individual organization … particularly has a participating … now or as we began to see if … accountable … but … issue is once ….

M
You're cutting in and out again.

John Lumpkin – Robert Wood Johnson Foundation – SVP & Director
Again, I apologize for my AT&T service on the East Coast. But now I have three bars. I should be better. Then when should there be coordination by the federal government? That's going to be specifically our role because we will be advising ONC for their issuing of their proposed rules, and any time we say what the role of government should be, there should be a behind-the-scenes question of why is this important for these elements.

Next slide: I'm not going to spend a lot of time talking about some of the existing governance mechanisms. We've all seen the handout materials.

Next slide: This particular approach is looking at the FACA and ONC process, of which we're a part of, making our recommendations to the HIT Policy Committee. There are standards and interoperability framework, existing laws, including HIPAA and other applicable laws, and regulations for e-commerce and Internet privacy.

Next slide: Then, finally, what we want to base this upon is existing or developing networks for HIE, as we just had a discussion. Then, finally, recognizing the federal procurement process, particularly related to HIE and the federal contracts, and wanting to move into a broader network that doesn't rely upon these contracts or grants to establish the ground rules and governance.

Next slide: What we want to focus then is on the gaps. Is there a need for a mechanism for the National Health Information Exchange Network? To define a set of criteria for the network across all exchange modalities, and these are the conditions for trust and interoperability based upon privacy and security, and to insure both the user and individual confidence in order to promote the exchange. Exchange will happen based upon trust.

A process for validation, this is where we begin to get into the issues related to accountability and to recognize trusted, shared, technical resources, for instance certificate authority and so forth. Finally, oversee and assure accountability for upholding conditions for trust, interoperability, and for the governance of mechanisms … on an ongoing basis. This is what our task is and the scope of the task.

Are there other comments related to that or questions, lack of clarity, areas where we think the scope is not clearly defined?

John Houston – Univ. Pittsburgh Medical Center – VP, Privacy & Info Security
John, how does enforcement fall into that, or does it fall into one of those categories we're going to talk about?

John Lumpkin – Robert Wood Johnson Foundation – SVP & Director
I think others can speak to this. I think that part of our recommendations have to talk about the issue of enforcement within a governance structure. There are obviously all sorts of mechanisms of enforcement from probably the weakest is being everybody who refuses to do business with that party. That probably doesn't build as much trust as if there is a governance mechanism to identify those who may not be adhering to all the policies and procedures. So when there is a mechanism for that, and that really is what we talk about with enforcement, it creates a climate in which trust can occur.

John Mattison – Kaiser Permanente – Chief Medical Information Officer
Yes, and if I can chime in, this is not necessarily a proposal, but it's just an illustration kind of mechanism could be involved. So let's just take a use case where one of the participants has revealed that they have a serious security issue on their side of the network adapter. One mechanism to minimize the risk associated with their local security risk would be to move their registration on the participating entity registration service so that they could not be addressed using the NHIN. So I'm not proposing that as a solution, but that would be an example of one mechanism to address issues that most likely they'll be around security. Does that make sense to others?

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst
Yes, it does, except for the assumption that the issues will be around security or, depending on how broadly you define security.

John Mattison – Kaiser Permanente – Chief Medical Information Officer
I assume ….

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst
…has had a— If a participant has had an employee who has breached, how have they dealt with it? The whole issue of sort of privacy policy seems to me as likely a subject for concern in this area, as the actual security measures.

John Lumpkin – Robert Wood Johnson Foundation – SVP & Director
Wes, I would presume that that would be subsumed within security, but that's layering out all the issues and all the hierarchy of violations and the hierarchy of sanctions is part of the governance process. I was just … a mechanism that would subsume a hierarchical policy of defects and sanctions.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst
I would not expect us to lay out that hierarchy. I would expect us to lay out the process by which that hierarchy were established and revised over time as situations warrant.

John Lumpkin – Robert Wood Johnson Foundation – SVP & Director
Right, but we would probably be involved with setting some sort of threshold to say they've done a wide open hole. We need to move them from our directory.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst
I don't know. I guess we need to go back to the man here and ask that question, but this is a whole area of the interface between policy and governance, and what do we, are we the initial governing body, or are we establishing the rules under which the initial governing body works? Are we establishing a set of rules that the initial governing body inherits to begin to work with? I think that's got to do with our scope.

Tim O'Reilly – O'Reilly Media – Founder & CEO
Can I ask just some framing questions because I am finding myself completely lost in this discussion? What outcomes are we trying to govern? What I mean, what situations? Are we trying to set up policies for security and privacy? I just don't have enough scope on what it is we're trying to accomplish. We're talking about governance mechanisms in the abstract, but for example, there's a whole lot of stuff that should be as ungoverned as possible.

I think, to me, the essential starting point is to figure out what are the things that absolutely need a governance mechanism, and what are the things that are effectively self-governed? For example, there's a whole lot of protocol level stuff where you go, yes, here are the protocols you're in, or you don't. Here are the protocols you're out. For example, that's how the Web works or TCP/IP. There's sort of a software layer, and you either adhere to the standard or you don't. There's no governance mechanism required other than, okay, we're managing the evolution of the protocol. If you're talking about security and privacy and the potential for bad actors, then you have a whole different set of discussions. I don't even know, sort of, what's the hierarchy of things that we're trying to establish governance mechanisms for?

John Mattison – Kaiser Permanente – Chief Medical Information Officer
At our last call, what I suggested is we want to do exactly what you just indicated. Define what it is that a governing body that's presumably designated by the NPRM itself and by the work of this group what it is that they should regulate at a federal level, and then what are the levers, and then what are the sanctions associated with that. That has to derive from the best policy platform available during this rulemaking process. So I agree, the "what we should," should come before the how we should and the levers.

Michael Matthews – MedVirginia – CEO
I'd like to add one other consideration that ties into this around scope, and that is making sure that our focus is on the exchange across what we currently call the NHIN and not the exchange that occurs within the participants on the NHIN, and where that line is drawn, I think, is going to be an important consideration. For example, Med Virginia itself has its own governing body that's accountable for the affairs within the local, but what I believe we're talking about here is exchange that goes across the network, and where we draw that line as imposed on Med Virginia is, to me, the critical issue.

John Glaser – Partners HealthCare System – VP & CIO
I want to second the suggestion that the "what" is at the essence of this conversation. I'd also give concern about the blurriness of the boundary between when the NHIN begins and ends on this kind of stuff. It may very well be that looking at the "what" that in fact there's not exactly a need for a body here. Like you said, there's a need for security and privacy, and there's a means to do that through the various committees, policies and standards that exist, and it's got an unfortunate capacity on meaningful use and other federal mechanisms that there needs to be some consistent standards for the exchange … data and transactions are a means for that. So it could very well be that a lot of the "what" is in fact handled to a degree.

Leslie Harris – Center for Democracy & Technology – President & CEO
I agree completely. That's what my questions earlier on were aimed at. I'm having a hard time sort of narrowing the scope of the "what" is it that is being governed here versus what is being enforced elsewhere, and that that would really help me think through whether we need a governance body, an independent body of committee of ONC or whatever.

Carol Diamond – Markle Foundation – Managing Director Healthcare Program
Yes, I very much concur. I think Tim asked the right question, which is, what is it that needs to be governed, and what is the scope of this governance? My worry is, until we really nail that down and bring that back to the committee, we're going to churn a lot on trying to figure that out either in the abstract or in raising various examples that may really just be distractions.

I have a suggestion to make, which is that it seems to me we need a very refined and clear scope for the governance recommendations that this group is being asked to make. If we can get that refined scope, it leads to where we were on the last call in then sort of looking at that and saying, so what exists today if governance is needed? What exists today … standpoint, in light of the fact that—

John Lumpkin – Robert Wood Johnson Foundation – SVP & Director
Carol, we lost you for about ten seconds.

Carol Diamond – Markle Foundation – Managing Director Healthcare Program
I'm sorry. What did you last hear?

W
…exists today, and then you went beyond that.

Carol Diamond – Markle Foundation – Managing Director Healthcare Program
Yes. What exists today and where the gaps might be. I think if we had that kind of almost done, preparation done for these discussions, it would really focus us on where there might be gaps in the context of a very specific scope and set of objectives for the governance. I have been struggling with these slides because, in the absence of that, it's very hard to envision how we can get to a set of recommendations.

John Lumpkin – Robert Wood Johnson Foundation – SVP & Director
Right. I think that we're all struggling with that because we're dealing with it in the abstract. Juggling the agenda a little bit, one of the things that I believe will enable us to, first of all, have more concrete discussions, but also to get our work done within the timeframe, is to have a smaller group of individuals who will in fact cone that down. Essentially put together a straw person listing of what we think those items are for which governance is importance. I've talked to a few members of the committee, Carol and John and Michael, who have agreed to actually do that sort of straw person framing so that we can have something to talk about.

Carol Diamond – Markle Foundation – Managing Director Healthcare Program
But, John, I would just say that one of the things that's going to be very critical is that ONC participate and charge our group with that refined scope. In other words, I don't think we can make it up. I think we have to take a hard look at what the "NHIN" is, what ONC's legal responsibilities and scope is, and try to, within that context, come up with something that can come back to the committee as a set of parameters under which these recommendations have to be made. In other words, I don't think the committee can make it up. I think there's a need for government to sort of refine the scope a little bit, I guess, is what I'm suggesting.

John Lumpkin – Robert Wood Johnson Foundation – SVP & Director
Mary Jo and Mariann will be working directly with that, and we've also gotten commitment from legal at ONC to help us understand what that scope is that ONC is discussing.

Tim O'Reilly – O'Reilly Media – Founder & CEO
What I'm looking for is something that's actually at the level of the meaningful use criteria, just like give us ten points. Here are the kinds of things that we are concerned about that could require governance, and some of them will have technical solutions, and some of them will have actual, you know, some governance mechanism. But we need to know what those 10 or 12 things that you're worried about are. And that's all. Just the list, you know, we want to look out for this situation. We want to look out for that situation. We're worried that this might happen, you know, and then we think about governance. But it's got to be in response to some concrete set of issues.

Steve Posnack – ONC – Policy Analyst
If I may chime in as well from ONC. So to your question, Tim, I think that's a fair question, and the reason why we've assembled all of you brave souls to help us out is to help address some of those points. So to the discussion that you've had thus far, one of the questions that we have in mind, and that we've heard over the past several years, and now with this new authority that's in the HITECH Act is, what do we need for exchange to occur? There are a lot of reasons why it doesn't, and if we can address those reasons through governance, than that will be a helpful outcome.

I can, in doing so, try to identify the processes and structures that can be used to address those issues for why exchange doesn't occur. As an easy example, if we think identity assurance across participants is an issue, what process or structure do we need some type of authoritative entity? I don't want to presume that there is a single body that would come up with governance policies. But going along those lines of thinking, and if you all could help us identify those areas that are impeding exchange from occurring nationwide, then you could also follow up and help us determine the processes and structures for how to best address them and govern them. And I don't know if that's helpful at all to anybody.

Linda Fischetti – VHA – Chief Health Informatics Officer
That's very helpful, so as I look at this, and I look at page 17 and 18, the existing mechanisms, I actually would title that slide slightly differently. I would make them contributing mechanisms. So there is absolutely a need. We see laws in here. We see regulations in here. We see technology in here. We see strategy and direction coming out of the federal advisory committees, and there is a need for a team to choreograph what this is going to mean for the nation.

How do we choreograph laws that get rolled into regulation that then the policy is written is such a way that the technologist can develop whatever needs to be changed or tweaked to meet the policy? How do we communicate to implementers nationwide that this is changing based on something, you know, that just changed in an e-commerce thing, and that 18 months from now you'll need to plan on an upgrade that's going to include these different things, as well as, oh, by the way, change your legal agreements. So it's really that choreography across all of these components that I, as an implementer of an NHIN, feel a large vacuum right now, and feel like it's a number of fragmented components, which then we end up having to sort of interpret internally, which of course has a very small footprint when we know that this should be a national conversation. Thank you.

John Mattison – Kaiser Permanente – Chief Medical Information Officer
I agree, Linda. If I'm trying to sort of start a list of the "what", what I think have been proposed as candidates so far are security issues … scope to be defined and, as Michael pointed out, it has to be security issues that affect what is defined as part of the NHIN as opposed to internal operations. As John Glaser indicated, I think, there's a fuzzy boundary there, but that boundary should be defined in terms of what the scope of influence and governance should be. Number one would be security within that scope. Number two would be data integrity within that scope, which would include the identity. I think that would rightfully include the identity management issues, but there would be other issues associated with data integrity that should be, probably could be managed in some way. The third that all suggest as a candidate for the "what".

We've got a lot of background noise, if somebody could go on mute. There's tons of background noise.

Anyhow, the third one that I would put as a candidate for the "what" would be an asymmetry of participation, so if a particular entity is requesting and receiving, but never responding to requests, that might be an issue for participation on the NHIN or not, but in terms of the "what" that we've talked about so far with that addition, I would say there's three: security, data integrity, and symmetry of participation. If that makes sense to folks as sort of a candidate list, not as a final list, are there other categories that anybody would like to propose in terms of what might go on that list?

Leslie Harris – Center for Democracy & Technology – President & CEO
What I hear you saying is this governance body is doing policy on things that haven't been resolved. But then when I've asked before, is this body just an intermediary for the policies that are coming out of the policy committee, etc., I never got a clear answer. Not all things are going to get resolved, so perhaps what you're saying is this is the body that has to work out some of these implementation things that we haven't thought of yet. Beyond that, I'm still confused.

Linda Fischetti – VHA – Chief Health Informatics Officer
Make sure that the appropriate stakeholder is, so if it's identity management, then maybe that comes out of the S&I framework on number two after the federal advisory committees have given that federal policy recommendations on that, and the coordination with Internet privacy. So I don't know if this governance group would actually have to do the work and stand up the technologists and all of that, but I do believe that there's a complete vacuum of cross-topics area or, well, I don't know. Maybe it's role … the topic, choreography of all of the players that are needed to make this happen.

Steve Posnack – ONC – Policy Analyst
Maybe this is too far in the weeds, and maybe it's not. As another example for the "what" list here, patient matching and a consistent approach across participants when they exchange information could be another area where you could say, we think we need governance there. It's currently implemented in a number of different ways. Obviously there are privacy issues along with those ways that some of them are implemented. Maybe that's part of a preferred approach that folks implement matching in a certain way.

W
Steve, but I would argue that's not a governance issue. That's a policy issue. There's a question of whether to make policy that's established standard level of assurance, but it's not a question necessarily ….

Elliott Maxwell
To respond directly to Leslie's question, I don't think this group is to make these decisions—

W
I agree.

Elliott Maxwell
—about those issues. I think what's being said or what's being asked is where are there areas where there are issues that need to be resolved in order for nationwide exchange to be promoted? In those areas, what decisions need to be made? Then this group would be saying, we suggest that the process for addressing these areas would be the following.

W
That is a clear statement, and I appreciate that. That's what I was hoping that we were going to get to. So then I agree with Carol's earlier comment. It is kind of difficult to be able to say this is the right process until you've scoped out the areas that you think we're going to be.

Mary Jo Deering – ONC – Senior Policy Advisor
I wanted to add that one of the background documents that you received was a work product from a public/private group last summer that tried to take a high level approach to what are the areas. What are the types of things that need governance? What are these functions of governance?

There's a table in that document that was labeled June 2009. For our public listeners, it is available on our Web site, and we'll make sure that we make that available to people. Again, it did try to take that sort of beginning look at what are the categories of activities where we see governance might be required? So that might be a candidate point for the group to take a look at to see how complete that is or whether there are gaps. Again, that document does not try to set policy, and it doesn't try to do the work that you've been asked to do, which is to identify the processes for addressing those areas. But again, it might be a starting point for you to feel comfortable with your "what" list.

M
I agree with Mary Jo. I've been reading the document, and there was a table at the back, correct?

Mary Jo Deering – ONC – Senior Policy Advisor
That's correct. There's a lengthy table too, and it goes and really spells out. First it spells out these functions at a higher level, and then it goes into a little more detail to explain what those functions are. Then the third column in the table says what would be the attributes of any entity that might be charged with overseeing this particular issue? Again, it doesn't try and name what that entity might be, but what would be the characteristics and capabilities of any type of entity that might be charged with overseeing that particular function, governance function.

W
This isn't the governance white paper that ONC and NHIC did?

Mary Jo Deering – ONC – Senior Policy Advisor
Yes. Right. Yes, but again, it had pretty wide public/private participation on it.

W
I want to make sure that we're talking about the same thing.

Mary Jo Deering – ONC – Senior Policy Advisor
Yes. Exactly. Yes, you're quite right. And the only other fine tuning point that I would probably make is that we don't assume any single, centralized governance entity, and I think most people on this call would have been surprised if they thought ONC did presume some governance tzar, so I did want to leave that on the table as well.

John Lumpkin – Robert Wood Johnson Foundation – SVP & Director
So other thoughts for those of you who looked at that table and the list that John Mattison was pulling together? Are there other areas that we think we ought to include on the list?

M
Mary Jo, if I could ask the question, who send that out, because I ‚m trying to pull it back up, and I can't find it? Was it send out by Mariann, or was that sent out by somebody else?

Mary Jo Deering – ONC – Senior Policy Advisor
It was sent out by Mariann.

W
…one of the early e-mails.

Mary Jo Deering – ONC – Senior Policy Advisor
I believe she sent out a series of three e-mails in a row the afternoon of our administrative call, and I do want to make it clear that that first call was just an administrative call. It was not really a working call, and so on Thursday, the 12th of August, you should have received three. Actually, I think there were a total of four overall.

M
There were four, yes.

Mary Jo Deering – ONC – Senior Policy Advisor
I think that might have been in the very first of the e-mails.

M
Okay. I remember reading it, but now I can't find it, so I apologize.

Mariann Yeager – NHIN – Policy and Governance Lead
I can resend it real quick, so you have it at your fingertips.

M
That was an excellent document.

Judy Sparrow – Office of the National Coordinator – Executive Director
Send it to Judy too, so I can have it posted.

Michael Matthews – MedVirginia – CEO
A couple of things to add, please: Whichever set of tasks we take on, let's go back to the basics. One of the real catalysts for having to go through this process is the fact that NHIN Exchange today is limited by only those who have a contract with the federal agency, and so whatever we do, we have to come out with some participation requirements that would enable others who would desire to exchange across the network, but who do not necessarily at this point in time have a contract with the federal agency.

The other point I would want us to continue to focus on is keeping a distinction between governance of the network and operations. It seems to me we're somewhat combining our language to encompass elements of both. I believe that our charge is around governance. It is separate, but a related issue around how is the operation actually going to occur? So to the extent we can focus on process and policy from a governance standpoint, we still, as a sector, need to identify some of the operational responsibilities. But again, in terms of the work before us, I'd suggest that we're focused in on the governance aspects.

John Lumpkin – Robert Wood Johnson Foundation – SVP & Director
Absolutely, but I think that as we engage in this process, we're going to need to come back probably a couple of times and look at what we're doing and then the list and say a couple of things. First of all, does it absolutely have to be there? Is it really a governance issue, or is it an operational issue?

Then the second is that we need to work on the issue of who does that after we figure out what it is. I think that's part of Leslie's question is that we haven't gotten to the point of saying what entity or, more importantly, entities would be engaged in this sort of governance process. Ultimately, we want to talk about the governance activities for which we believe ONC needs to be engaged in, either directly or through … ONC … involved.

W
Right. I mean, I guess that's the "what". We've said we're limiting this to activities that ONC is involved with, but then we have to further come up with this list of what, and then limit it to the ones where we think that we need some additional governance. I just feel like they've kind of stepped through it in that order.

M
But I think the document that Mary Jo referred to earlier that Mariann had sent out is a really excellent, comprehensive list of what, so perhaps the subgroup can comb through that, informed by the discussion today, and come back with a recommendation for what perhaps even offline for some offline discussion prior to our next formal call.

Laura Adams – Rhode Island Quality Institute – President & CEO

I just want to be sure that we're defining the "what" the same way and not to split hairs or confuse the issue, but I think there's a question of what needs to be done and what is being governed. I support Linda's comments earlier and Carol's comments about the need to understand kind of what are we governing here, and in a really clear sense.

John Lumpkin – Robert Wood Johnson Foundation – SVP & Director
I'm trying to get my arms around the last question. In a sense, what we're governing, as my understanding, is what is now the National Health Information Network, the NHIN, which is exchanging; is a framework for exchanging information between participating HIEs through contract or grant. Where we want to go is to be able to expand that network to encourage exchange to others who would participate through that. But this will not constitute the entirety of exchange that will occur of health information.

Laura Adams – Rhode Island Quality Institute – President & CEO
When we talk about the activities that the ONC is engaged in, we're talking primarily about the NHIN Exchange, as we know it right now, or personal health information?

Mary Jo Deering – ONC – Senior Policy Advisor
I'd like to maybe step in. I think that very clearly that is one of the triggering factor, and you're all correct to say that at the end of the day, we really look forward to your proposals that will accomplish that. I don't believe it is ONC's intent to limit you to only identifying governance activities for what is currently known as the exchange. That is one model of exchange. We have other activities, other models of exchange.

Certainly many of you know that there's a directed, secure routing model, which is being explored and going to be moving into operation. We have already national models of exchange that are taking place: labs and related to pharmacy activities and others. So we did not ever intend to limit you to simply saying what we want you to do is correct the problems with what has been in the past known as the exchange. But correcting those problems is absolutely essential.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst
I guess that raises an issue of what do we do when? Is all of this on the schedule that John presented? Is it still going to be all done? Still going to have a long vacation between mid October and the second quarter of next year?

John Lumpkin – Robert Wood Johnson Foundation – SVP & Director
Yes. I think it's going to essential for us, as we start to focus in because we have a very short timeframe for doing this is that we pretty much focus in on the first task, which is the exchange, as it has been developing. What are the governance issues that will enhance the likelihood that people will exchange this? We will run into governance issues that will be overwhelmingly clear that they go beyond the scope of the NHIN, but we need to address it within that context. But if we don't have some sort of way to draw a circle around what our task is, we will not accomplish it.

Carol Diamond – Markle Foundation – Managing Director Healthcare Program
There are a thousand things I want to say right now, but I'm only going to say one, which is that I think it's really important that the scope gets defined in a way that does not mix the particular model … NHIN … but rather is defined in a way that speaks to ONC's authority and scope of this responsibility in a governance structure. I'm worried that there are many elements of information exchange that are going on under the auspices of ONC. There's meaningful use. There are a whole host of things we discussed that are "information exchange" or "information sharing." I want to make sure that the way we define it is in concert with ONC's authority and responsibility and oversight and not confounded by lots of other ways that might be out there to do a whole host of things because I think we fail to make a list of that, this committee will need to go for a couple of years.

Mary Jo Deering – ONC – Senior Policy Advisor
Carol, I wanted to pick up and actually I think, if you look at that table in the white paper last summer, you will see that it probably speaks to the needs that you're all asking for. Since the goal is to identify governance functions, many of the functions of governance are really irrespective of the model of

exchange. So, as you look at that preliminary list that was drawn up, I think you will be able to determine for yourselves, is this what we want to draw a governance structure for?

It could be that you look at that list and you'll say, wow. This is a terrific list. I can't think of anything to add to it. If we came up with a process for governing these functions, we would be comfortable that we've done our duty. That's just hypothetical.

You might come up with that conclusion. You might say, gee, this is only some of them, or we want to throw out half of them, or we've got other concerns. But I do think that you might feel more confident if you took a look at that and saw whether it helped you actually do the framing that you're asking us to do now.

Carol Diamond – Markle Foundation – Managing Director Healthcare Program
Yes. I'm familiar with that paper, and I agree that governance functions are one dimension of the scope that should be refined. Another dimension here is the scope of what ONC has the authority and the need to do now. So for instance, do those functions apply only to federally funded information exchange, whether it's through incentives or grants or what have you, or are they meant to apply more broadly? You just mentioned earlier … and other networks that might exist. I think there are some critical … questions that need to be answered in order to get to these questions that you're asking us to answer.

Mary Jo Deering – ONC – Senior Policy Advisor
That certainly is a very fair response, and I do hear you. I think that perhaps as the small group, we would have perhaps a very quick, initial, convening meeting of the small group with the ONC staff where we could talk this through, or we would certainly try to help achieve that finer, the refinement of the scope that you're asking for. But I do want to say that we look to you to tell us what is it that needs to be governed, and we do not want to be limited by any one, you know, existing entity per se.

Elliott Maxwell
One other comment about the scoping piece, and that is that there have been really very different levels of abstraction about the questions that need to be addressed, and the more specific one can be about what are the places where there are obstacles for exchange or issues that need to get resolved. The more concrete that is, the more—that, combined with a kind of broader and more abstract categories of governance can be very helpful because that can give you a much greater focus on what needs to get resolved now, and then to figure out the process of how to get it resolved, who should be involved in the resolution and the like because it ranges from how do you extend membership to the present exchange to how are hard decisions going to be made about trust in general. Those are quite different levels of abstraction, and if they get too abstract, then the discussion will be abstract about is there a governance mechanism for trust as opposed to how do we make sure that people know that they're communicating with parties that they believe they're communicating with?

W
Just to be clear, our job is to come up with a governance structure to make decisions about things like identity management, but not to come up with a plan for identity management.

Elliott Maxwell
I think that's right.

W
Okay.

Elliott Maxwell
Yes.

John Lumpkin – Robert Wood Johnson Foundation – SVP & Director
So it seems to me that there are a couple of things that we can be doing as we're trying to pull all these pieces together. One, I've heard a number of comments made about identifying those kinds of barriers

that a governance structure could help facilitate or help remove those kinds of barriers to exchange. The second is that there are a list of areas for governance that were raised in the white paper. I think that all the committee members should be looking at that, and then seeing if there are areas that are not included in that list or areas that are on that list we think ought not to be there, and that we can use that to also start scoping in, while at the same time a smaller group will be meeting, working with ONC staff to create a straw person document or outline that we can use to really cone down on what our tasks are.

Leslie Harris – Center for Democracy & Technology – President & CEO
A quick question: If you took the white paper, and you took the DURSA, and sort of laid them on top of each other, even though they aren't for the same purposes, would you find that it aligned pretty well in terms of how they've identified? I obviously understand that they are for different purposes, but would you find that the DURSA … trust frameworks for national health exchange. Would you find that they more or less identify the same things for governance? Has anybody done that?

Mary Jo Deering – ONC – Senior Policy Advisor
I will just jump in and say that Carol was quite right that the DURSA addresses only certain aspects that need to be addressed in creating trust and security in information exchange, so there would be a partial overlay there, partial in both ways in that there would be some things that would overlay, and then there would be some that are external in each, you know, that aren't covered by the others.

Leslie Harris – Center for Democracy & Technology – President & CEO
I tend to think in Venn diagrams.

Mary Jo Deering – ONC – Senior Policy Advisor
Yes. Exactly. That's exactly what it is. There's a Venn diagram, but each document has some areas that are outside of the combined.

Leslie Harris – Center for Democracy & Technology – President & CEO
Okay.

John Mattison – Kaiser Permanente – Chief Medical Information Officer
I apologize. I dropped the call for about a minute and just got back on. But what was said about a minute and a half ago about the charter of this group is to focus on the structure of a governance body. What I'd like to suggest is that since form does follow function, what that governance body looks like and who should be represented on it, I think very much should reflect the kinds of issues that will be governed by that body. So I still think we're stuck with a "what" first. Given that we have a really excellent list in the document created by ONC and NHIC last year, one of the things we can consider doing is going item-by-item on that list and develop a matrix.

The other axis of that matrix would be existing policy, governance, regulatory, technical committees associated with HIE, and identify where each of those might most properly be located as a policy, a standard, a governance issue, and so that we know that everything has a place, and everything is in its place. Then that might help us frame the discussion in a way that we can say, well, these are the issues that fall out that really look like they do belong with the kind of governance body that we're chartered with defining, whereas these other things, while important, and while essentially, have a better loci for placing them as policy issue or as technical issue or as any of the other, as a conformance or compliance issue, whatever. But I think if we go through an exercise with that matrix, that might help. Does that make sense to others?

Carol Diamond – Markle Foundation – Managing Director Healthcare Program
I also think a matrix could be helpful, but I would offer that there's another column. I mean, one column is sort of policymaking responsibility in a nutshell, and that's certainly one element of governance. There's another column, which is what I'll lump together as oversight, accountability, and enforcement, which is a different element. A policymaking entity may simply promulgate policy, but not be the same entity that knows whether or checks whether or has a responsibility to enforce those policies.

John Mattison – Kaiser Permanente – Chief Medical Information Officer
I totally agree, and I think that would fit within that matrix. I totally agree, Carol.

M
I think that's absolutely vital to what Carol said. That's how we expand it to make it meaningful.

Mary Jo Deering – ONC – Senior Policy Advisor
I'm going to channel Carol again and say that I heard her add the very important, almost, I hate to call it a fifth column, maybe we're up to a sixth column right now, which is, or maybe it belongs into the third column that John was describing when you look at existing structures. What I'm getting back to is those areas where ultimately ONC might have the authority to act. Again, as John pointed you out to one of those slides, your priority focus is ultimately on areas where ONC would have the authority to act through this NPRM. On the other hand, for you to identify important areas that might fall outside ONC's area, but that need to be addressed somehow, it's perfectly appropriate for you to at least identify those and flag those.

Carol Diamond – Markle Foundation – Managing Director Healthcare Program
Actually, one other comment I was going to make was that while that table does list the governance function, functions are not governance objectives, and I think we would have to go through those functions and say, what are the objectives in each of these areas, whether limited by ONC's authority or simply the need of today's NHIN … going on, and try to refine those into objectives because functions are also abstractions. And we need to get very clear about what specifically in the context of those functions we're talking about governing.

Mary Jo Deering – ONC – Senior Policy Advisor
I agree.

John Lumpkin – Robert Wood Johnson Foundation – SVP & Director
I think that we seem to be clarifying some of the paths that we need to accomplish, as we move forward, particularly around using the table that was in the white table, as well as collecting additional, any additional items that we determine that there may be obstacles for which governance may help facilitate exchange, taking that task, and then coning down, while we may identify areas that are outside the area of authority of the ONC, but focusing then on that area of authority. Are there further comments, or are we ready to move on and talk a little bit about the hearing?

Hearing none, if we could go onto the next slide, we've had a hearing. Actually, we have a hearing scheduled on the 28th, and our goal today is to look at the proposed panels, recognizing that this is going to be a parallel process. What we want to be able to do is use the expertise on this panel to develop the document, but we also want to hear from the field. The purpose of the hearing is to give us an opportunity to have those who are not on the committee give or help us develop some of the insight. So, today, we want to talk about the panels, what is it that we want to get out of each of those panels, and then identify the questions that we would want the panelists to address, and then we'll follow up with e-mail and ask each of you to make suggestions of who you think would be good, the best ones on the panel.

On the next slide, what we have the listings … panels … hearing, and ….

W
You've broken up, John. We lost you.

John Lumpkin – Robert Wood Johnson Foundation – SVP & Director
What I was saying is do these panels seem to be about right? Am I still on?

M
Yes, you're on.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst
Yes. I guess I'm not sure what panel one is about. I think, W3C, we know what they do. ICAN, we know what they do. Are we talking about banking, about standards for banking, or the operation of ATM networks? And telecommunication is sort of the same issue. I guess the answer is yes, to a certain extent. But I think this panel, starting with W3C and ICAN, looks a little SDO oriented, so I'm trying to figure out what its intent is.

Leslie Harris – Center for Democracy & Technology – President & CEO
I guess I'm trying to do that too. I mean, W3C is sort of about standards. I'm not sure we're hitting any entities that sort of … other sectors.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst
I would argue that the ATM network.

Leslie Harris – Center for Democracy & Technology – President & CEO
ATM.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst
Credit card networks.

Leslie Harris – Center for Democracy & Technology – President & CEO
Yes.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst
I mean, they're different in that they're very, very transactional.

Leslie Harris – Center for Democracy & Technology – President & CEO
Right, they are transactional.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst
But on the other hand, they have a lot in common too.

Tim O'Reilly – O'Reilly Media – Founder & CEO
Yes. I have to say I would agree that looking at financial markets certainly makes some sense because there is a set of very, very concrete things that need to be regulated and that need oversight. I would just say, in the Internet context, the W3C is largely regarded as an irrelevancy by most people.

W
Yes.

John Lumpkin – Robert Wood Johnson Foundation – SVP & Director
Is what? Is regarded as what?

Tim O'Reilly – O'Reilly Media – Founder & CEO
An irrelevancy, and ICAN is regarded as a disaster, so looking at either of them as a model would be very unwise.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst
Tim, is there a governance entity in the Internet that you would regard as less so?

W
No.

Tim O'Reilly – O'Reilly Media – Founder & CEO

Not really, no. I mean, I think the original IETF … but again, this is all just sort of technical standards work, and I don't think this is a technical standards set of issues.

Leslie Harris – Center for Democracy & Technology – President & CEO
I agree completely. IETF may have worked reasonably well, but it's just irrelevant.

Tim O'Reilly – O'Reilly Media – Founder & CEO
Yes. Exactly. It's not really the same class of problem, whereas sort of financial exchanges absolutely are. You have the possibility of bad actors. You have requirements. There might be some things in the Internet in the sense some of the pairing arrangements that are done at the provider level, and so some of the regional Internet pairing associations. I'm not even sure. You know, sort of my sort of visibility into that level is back to the 90's when that was all sort of hot and heavy, and I don't really know how important that is in today's world, but there may be some history there that might be relevant.

Leslie Harris – Center for Democracy & Technology – President & CEO
I'm just … that's going to lead us off down a rabbit hole that I'm not sure is terribly relevant. Financial services is relevant.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst
I would argue that e-commerce would be relevant.

Leslie Harris – Center for Democracy & Technology – President & CEO
And any kind of voluntary. You've got all kinds of voluntary initiatives around e-commerce.

John Glaser – Partners HealthCare System – VP & CIO
Yes. When I was at ONC … talked to a Harvard Business School professor and studied the MasterCard/Visa infrastructures and how they govern that. I'm blanking on the guy's name, but Sashin might know. I thought it was an interesting model about how one governs thousands and thousands of banks and hundreds of thousands of merchants to play by the same rules.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst
Yes, that's a good model for healthcare with small practices and large institutions.

W
Right.

Linda Fischetti – VHA – Chief Health Informatics Officer
I know that this is a very weedy suggestion, and this is Linda from VA. But what we may want to do is actually by the time we reconvene and we have our hearing, we will be live with an expanded B32 data set and with Kaiser Permanente and Med Virginia. We may want to actually do a demonstration of what it is because I think that there's a lot of conversation out there in industry about, oh, you can't do it, and it's too heavy, and the key is that we're as close as we've ever been to being semantically interoperable, something that we've all worked two decades on. Actually, we truly do need governance to come in and make it a lot easier, and I think that Doug Fridsma is doing a lot of that over at the Office of the National Coordinator. But we might want to just spend, even if it's only 20 minutes, on what the "if" is.

Laura Adams – Rhode Island Quality Institute – President & CEO
I would second that because I'm hearing an awful lot of, well, this thing was a failure anyway, and this is because there's a line in HITECH, and that's why this has to go on. There isn't anything to govern. We don't know what we're doing with this because the system doesn't work. So I do think that would be very, very helpful.

John Lumpkin – Robert Wood Johnson Foundation – SVP & Director
I just would like to focus on the function of the hearing. The hearing really is for us to listen to the field, as opposed to convince the field that what we're doing is meaningful. I'm not sure, and this is the group to

answer that question whether or not, we on this phone, believe that there is a reason for us to do it. As much as I'd like to see a demonstration, I'm not sure if that would be the best use of 20 minutes.

M
I think the issue is as long as it's a comparable analogy, I think it's valuable. But I think what I'm hearing is that not everybody is sure that there's a comparable analogy.

Mary Jo Deering – ONC – Senior Policy Advisor
If you move to panel two, it could be that rather than necessarily a demonstration, that the people, both in varying levels and in varying ways who are exchanging information, instead of demonstrating what they're doing, they get to the issues that Linda has just said. Here, we are doing it. Instead of just showing you what we're doing, we're going to talk about what our experience is about what we have, what we don't have, what we need. So I'm just thinking that Linda's purpose might be accomplished possibly through panel two if you choose to keep that.

Doug Fridsma – ONC
Every single one of the issues that we've raised as being kind of priority items that we want to try to address with governance has come up in real world situations that we've had to kind of come up with solutions to deal with. I think there is a lot of value in making the kinds of issues that we've raised absolutely concrete. So if for no other reason that it provides a backdrop or a framework for the more abstract conversations to occur, but in whatever network or format we decide to have information exchange occur, the things that we're doing right now in terms of trying to enable exchange will happen … exchange or direct or some other form of getting the information flowing. We've always said we want to make sure that when we do these things, we don't do them in the abstract, that we have it grounded, that we make sure that we address real problems. So I think there is some value in at least having that conversation.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst
Not to pile on, but I think there are two other values that we should pay attention to, having been a member of the panel and a member of the group listening to the testimony in a number of cases now. One is that even if the exact presentation is material already known to the committee here, the workgroup, the question and answer tends to do a lot to help sharpen up the understanding of the problem or the issues on the workgroup. Second, it's been my experience that people who testify after that often have a better understanding of the context that we're interested in as a result of it, and they actually at least modify their verbal comments in the course of the day. I think, as sort of an enhanced statement of the agenda, it makes a lot of sense.

John Lumpkin – Robert Wood Johnson Foundation – SVP & Director
Let me just suggest something, and this may be completely off the wall, and no one is going to like this idea. But taking all of the comments that I just heard, I wonder if the structure that we have is right and whether or not we might want to start off with that first panel, as we've had, and was looking at some other models and other domains. What I heard was e-commerce and banking as being two examples. Then we have a series of panels with people who are actually engaged in health information exchange, and we asked them to focus in on the issues of trust, interoperability, accountability, and enforcement and oversight. Rather than cutting it by the topic area, we cut it by some people are actually doing it, and ask each one in a series of panels what their experience is, what they see as their obstacles, what they see as the needs.

Linda Fischetti – VHA – Chief Health Informatics Officer
I think that would be very useful.

John Houston – Univ. Pittsburgh Medical Center – VP, Privacy & Info Security
I agree. As long as we get them in the context of speaking or at least providing a philosophy of what it's going to take at the level of an NHIN, I think sometimes oversimplification occurs, and what we need to do is try to get these people to translate what it's going to mean, you know, their experience in what it means in terms of what it's going to take for governance in the NHIN environment.

Linda Fischetti – VHA – Chief Health Informatics Officer
I would like to echo what you just said about the emphasis within the NHIN environment. I was just in a meeting with a vendor system yesterday who is so married to legacy systems and the capability of legacy systems that that's really what they wanted an instantiated going forward. Here we have an opportunity like none of us have had in our careers to really leapfrog forward on our watch, and it was, you know, so I think that it is important. We're charged with NHIN governance. We should in fact embrace the concept of NHIN and the utility of NHIN, and not sort of entertain the broader concept of, well, is it NHIN Direct, or is it NHIN, because from our perspective they're completely different use cases. And we need both of them, and we need whatever else will come up next, so I like your comments. Thank you.

John Lumpkin – Robert Wood Johnson Foundation – SVP & Director
Other thoughts on the structure of the workgroup of the hearing?

M
…suggestion….

Carol Diamond – Markle Foundation – Managing Director Healthcare Program
Sorry. I heard someone else speaking. I was going to say, I like the idea. Since we have such a short time in this workgroup, I like the idea of using the hearing to provide the group with a kind of input it needs to get to recommendations as opposed to, you know, just trying to have people address the broad issues of governance. I think one thing, to Wes' point, that we've learned is that the more specific we can make the request in terms of the input we want to hear, the better information it can be. I like the way you broke it out on trust and accountability, etc., all the basic elements that we're discussing as opposed to saying something who is engaged in information exchange, you know, can you tell us about governance. I think we have to get specific and say in these areas, what can you tell us, and what does it mean for, what do you think it should mean for ONC, as we begin to look at the issue of governance. But given them those specific categories to really talk about.

Christine Bechtel – National Partnership for Women & Families – VP
I agree with Carol, and I was thinking about, in terms of governance for trust, the area of governance that I have a particular interest in, and you won't be surprised to hear this, is the role of consumers in governance. So, as we think about trust, I'm wondering if in that panel we might have some folks address the way that they have included multiple stakeholders in governance and the way that they have supported them in participating effectively, which is particularly important for consumers or the challenges that they have faced in supporting effective participation.

John Lumpkin – Robert Wood Johnson Foundation – SVP & Director
Christine, just sort of as we're trying to work this or if you agree with that, then you would think that taking your comments that when we ask each of the actual implementers about the trust aspects of governance that we would want to ask each one of them in the separate panels to what extent are they engaging multiple stakeholders, including consumers.

Christine Bechtel – National Partnership for Women & Families – VP
Yes, and what challenges they have faced or what enablers they've identified to support effective participation. Exactly.

Michael Matthews – MedVirginia – CEO
Again, I'm going to come back to the point of the issues within the HIA versus across the NHIN network. More importantly, we have just gone through with the NHIN Exchange participants a compilation of lessons learned from each of the exchange participants, and there were two fundamental questions posed to the group. One is what enabled the participants to develop trust to exchange with other participants. What were the parameters and conditions and so forth? The second was related to what can the federal government do to promote trust for the exchange, what would the federal government do that would inhibit the trust amongst the exchange participants? That data has been compiled and could help inform the discussion going into these hearings.

John Lumpkin – Robert Wood Johnson Foundation – SVP & Director
Can you send that to the workgroup?

Michael Matthews – MedVirginia – CEO
I think what we can do is, we'll work with Mariann and Mary Jo to craft maybe the summary of those findings in a way that would help inform, but still not violate the … around the individual submission. Yes, I think we can do exactly what you're asking for, but we'll put it in a little bit different format than the one that currently exists.

John Lumpkin – Robert Wood Johnson Foundation – SVP & Director
Right. I think what we need to do is fairly quickly work up a set of questions for each of the group of panelists. Do we want to just have a series, let's say, of three or four panels of people who have experience with exchange, or do we want to have the panels, let's say, one panel be a couple of HIE's, one panel that may have particular stakeholder groups that are engaged in the HIE, all of them addressing the issues of trust and interoperability, accountability enforcement, and oversight?

John Houston – Univ. Pittsburgh Medical Center – VP, Privacy & Info Security
I think my personal hope or desire would be that we lean heavily on organizations that have implemented exchanges because I think that's what I personally think we're going to get our best information. We're going to get a lot of information, I think, from otherwise, and I'm not sure how informative that's going to be for, I think, the group that's here. We've heard a lot of that already as a lot of the issues that shape governance. But I think implementation of governance is really where we're going to get. I think, through people's implementation exchanges, that's where we're going to get the real information regarding how to do it.

John Lumpkin – Robert Wood Johnson Foundation – SVP & Director
One way to do that is we have basically four panels that we're talking about doing. We could have four entities that are implementing exchange, and we could ask them to bring maybe two or three people from their governance board so that maybe they have their executive director and one or two people from the governance board that will give us some different perspective.

John Houston – Univ. Pittsburgh Medical Center – VP, Privacy & Info Security
I think that would be of help to me. The other question I have is that by breaking it up by the different panels, you may find that one group has a lot of experience in multiple areas of governance, and they're going to speak to one of the three or the three that you have outlined here for panels three, four, and five, and I don't know how you'd deal with that.

John Lumpkin – Robert Wood Johnson Foundation – SVP & Director
My thought was that we would probably ask the panels, those who are implementing exchange, all the same question. And then what we would try to get out of this is a better understanding because it will be different perspectives of what are the critical governance issues to them.

John Houston – Univ. Pittsburgh Medical Center – VP, Privacy & Info Security
Or maybe another way to do it is ask questions up front. Ask them to respond about, and based upon the way they respond, put them on different panels, so we can have topically sort of similar. You know, group the panelists together by individuals who have sort of similar thoughts or similar areas of focus.

Laura Adams – Rhode Island Quality Institute – President & CEO
I think I might be confused again. It sounded like a moment ago we were talking about the panel each being sort of somewhat exchanging, and then them addressing what they're doing in each one of these domains or in each one of these areas, versus the areas separated out. Have we decided yet? I'm not sure which direction we're going. I think there's real value in both, but I think particularly the idea of having an individual entity addressing all of those because I do think there's interplay between them. So to address one area outside the context of the other, I don't think gives us the richness of the experience that we might get otherwise.

John Lumpkin – Robert Wood Johnson Foundation – SVP & Director
I think we have heard two different approaches to getting engagements by those who are doing exchange, and maybe we can just get a sense of the folks who are on the call.

John Houston – Univ. Pittsburgh Medical Center – VP, Privacy & Info Security
I agree with that last statement. It was probably more articulate than I would have said it.

John Lumpkin – Robert Wood Johnson Foundation – SVP & Director
So then we're talking about maybe three or four panels, each of the panels being a group that's engaged in exchange, which would include their executive director and then a couple of their leadership group who would answer a sort of standardized panel that would address the issues, as we've listed. Is that the sense of our group?

W
Sounds good to me.

Carol Diamond – Markle Foundation – Managing Director Healthcare Program
The only thing that occurs to me, just sort of thinking through this a little bit more, is that while it's very good to get input from people who are engaged in information exchange today, my sense is that just thinking ahead to our own work that it would also be good to put on the panel or create a panel of entities today who are performing governance functions, either policymaking or oversight in the true sense. In other words, not just from the "implementers", but those who the implementers are seeking or getting that kind of either policy or oversight from. It just seems to me that we ought to think about that as well.

John Lumpkin – Robert Wood Johnson Foundation – SVP & Director
Who … be thinking about doing that with …?

Carol Diamond – Markle Foundation – Managing Director Healthcare Program
Well, I'm sitting here. We've certainly talked to several exchanges, but having seen that sort of first set of tiger team recommendations, for instance, come out on some policies for privacy and security and whatnot, it seems like whatever bodies there are today who are performing some of these critical functions, we may have questions for them too. In other words, the issue here is also that the work is not complete. In other words, there are more areas to cover in each of the dimensions of governance. There are some entities, say, who are performing some of those functions that may or may not fall in our recommendations as bodies who need to do more, do less, transition. There are a bunch of moving parts here, I guess I'm saying. And it's good to hear from the implementers. But I also think, because I'm envisioning this mapping of the governance matrix, and then starting to fill in some of the boxes of who is doing what, leading us down the path of saying, you know, there's a particular gap here or there's a particular gap there. And we may want to get the input of some of the organizations that are performing some of those functions.

John Lumpkin – Robert Wood Johnson Foundation – SVP & Director
I think that sounds interesting. I guess I was trying to get you to be a little bit more specific. But if we were have, let's say, a final panel, of those groups that are doing some of the governance function, who would you be thinking about inviting?

Carol Diamond – Markle Foundation – Managing Director Healthcare Program
Yes. So I think if we thought about the matrix—on that matrix in terms of both policymaking and oversight, we would have potentially ONC, OCR, even FTC on some of the consumer access elements. There's the question of, are the FACA committees permanent policymaking bodies? Is privacy policy in perpetuity going to be coming from a FACA committee, or is there a question about where that lives longer term since information exchange is a journey, not a destination. There'll be more and more needs as time goes on, and I think one of the things that this exercise is going to result in is some questions about where these functions live long term.

John Lumpkin – Robert Wood Johnson Foundation – SVP & Director
Would you include in that the coordinating committee that's been created under DURSA?

Carol Diamond – Markle Foundation – Managing Director Healthcare Program
Yes, and I would include in that some of the states that are doing some of this. I mean, I think there are entities today that are performing some of these functions that we might have questions for when we try to fill out the matrix.

Laura Adams – Rhode Island Quality Institute – President & CEO
Let me just see if I can clarify this. Would it be something, and I'm not suggesting this is what we should do, but for example in Rhode Island, we have both the state law, and we have the regulations promulgated now. Would you be thinking about not only sort of the IRQI as the implementer, but also the state government that does the regulation of that, just for an example? I'm not suggesting that be on the panel, but is that what you were thinking about in terms of some of the exchanges?

Carol Diamond – Markle Foundation – Managing Director Healthcare Program
Yes. For instance, let's say there was a question that had to do with where the line was between federal guidance and ONC governance versus what states saw as their process or their role. It might be good to hear from some of those states who have been trying to perform some of those functions or see it as their responsibility to perform those functions.

John Mattison – Kaiser Permanente – Chief Medical Information Officer
That's very much what I had in mind when I proposed that matrix is that some of these issues that need to be governed somewhere might best be governed naturally at a federal level. Some of them might best be governed at a federated state level or even at a lower level of granularity. It comes back a little bit to the question that Michael asked early is where do we define the boundary between an HIE and international operations. But I think that matrix should accommodate any entity that could or should have a role in managing any of the issues that we need to manage on the vertical column of that matrix.

John Houston – Univ. Pittsburgh Medical Center – VP, Privacy & Info Security
I think it would be good to hear from those types of entities as long as they are entities that are actually in a position of actually having current accountability for doing those functions. I mean, trying to get experience, you know, a lot of dialog for people who have experience.

M
Right. And Holt Anderson would be a great source for that with what he's been doing with NCHICA.

John Lumpkin – Robert Wood Johnson Foundation – SVP & Director
I'm trying to get us focused then on our task at hand then. What I'm hearing is maybe the hearing would look like this. Panel one would be the monos and other domains: banking, e-commerce. Panel two and panel three would be a set of implementers, perhaps two HIEs or those who are doing exchange with some members of their governing board. Panel four and five would be some organizations that are currently engaged in governance at the state and at the federal level.

M
Agreed.

M
Yes.

John Houston – Univ. Pittsburgh Medical Center – VP, Privacy & Info Security
And I think what you might want to do then too is allow, if there are individuals who have an interest that doesn't fall into one of those categories or simply wants to speak, I mean, I guess you could allow people five minutes to present other aspects of governance if they feel strongly about it that don't fall into those categories.

John Lumpkin – Robert Wood Johnson Foundation – SVP & Director
I'm not sure presentation would be the best format. I think what we should do is maybe invite people to submit written comments.

John Houston – Univ. Pittsburgh Medical Center – VP, Privacy & Info Security
That's a good alternative as well. I just want to make sure that—I'm sure there are people out there that feel strongly about governance who want to say something.

Mary Jo Deering – ONC – Senior Policy Advisor
John, John, and John, I remember back when you were both on NCVHS, and it was almost a blessing when we lost one of you. We had three Johns more recently in ONC. Anyway, when we send out the federal register notice for this hearing, we had planned to publish the list of questions that you are asking for testimony about and encouraging people to submit written comments just as a result of reading the federal register notice. So just to let the workgroup members know that you'll have that additional input to look at too.

John Lumpkin – Robert Wood Johnson Foundation – SVP & Director
I think it's going to be a little bit hard at this point. So what we have then is we have the five panels, and then it seems that we're looking at governance for trust, for interoperability, accountability, enforcement, and oversight. We need to develop some questions that are perhaps a little bit more specific than that. I think what we're going to need to do is if you could e-mail those questions to Mariann and Mary Jo, we can get a candidate list that will be circulated very quickly. The second thing we need is suggestions for each of those panels, if you could e-mail those because we do need to get the invitations out post haste given that we're looking for a September 28th date. Is that doable?

Mary Jo Deering – ONC – Senior Policy Advisor
John, did you want to set a recommended time for them to give us that input?

John Lumpkin – Robert Wood Johnson Foundation – SVP & Director
I was thinking Wednesday of next week. I hear no complaints, so I think that will be the timeframe. I don't have anything else on here. Hearing none, let's move on to next steps. Under that area, I think we pretty much have covered most of the discussion that we have about drafting the recommendations. As I've mentioned, we have a small; we're pulling together a small subgroup that will be working with staff at ONC to help get us a straw person, you know, at least an outline that we can then discuss on the weekend of October 4th. We have ….

W
Could someone advance the slides for those who are watching this?

John Lumpkin – Robert Wood Johnson Foundation – SVP & Director
Yes. I don't have the slides readily available to me, so that's why I'm fumbling a little bit.

W
John, would you like me to just read what was on some of those next steps for you?

John Lumpkin – Robert Wood Johnson Foundation – SVP & Director
No. Actually, I have them here, but I just had this one other sheet of paper I was trying to find. I'm sorry. What we have on the subgroup, we already got agreements from Michael Matthews, John Mattison, and Carol Diamond to work on that. I just wanted to see if there was anyone else who had a strong desire to participate in that.

Okay. Hearing none, what we'll do then, as we have on this slide, so the subgroup will be working. We're going to have a meeting the week of October 4th, probably a conference call to discuss that initial outline, and then we'll work on that. There'll probably be a need for maybe an additional call before we give our recommendations on October 20th.

Following that, on the week of the 25th, we'll get back together. We'll get the feedback from the policy committee. If necessary, we will have an additional work call to get our final recommendations in to the policy committee on the 19th. Any questions on the next steps and timelines on that?

Mary Jo Deering – ONC – Senior Policy Advisor
Joy, are you still on the phone, Joy Pritts? Are you on the phone? I wanted to share with this workgroup some activities in another workgroup that are very complementary to yours, and this is the privacy and security tiger team that Wes and Leslie and Carol, and I can't remember anybody else sits on.

John Houston – Univ. Pittsburgh Medical Center – VP, Privacy & Info Security
John.

Mary Jo Deering – ONC – Senior Policy Advisor
And John, so I wanted to just let you know of some of the proposed complementary of their work. The tiger team has already submitted some recommendations in the areas of privacy and security, and at the risk of telling Carol and Wes and Leslie and John things that they didn't know already because this was just something that we've been discussing for a little while, we do see a role for the tiger team in looking at key governance. I was hoping to identify what might be key areas of privacy and security that need to be included in any governance activity, and so Carol, again, our apologies. This is just something that we are proposing as of today. It occurred to us there's a very nice synergy between the two groups. And so, in a way, there'll be some added depth and input from the privacy and security tiger team whose input then can be shared with the governance workgroup.

I can, at a later time, go into more detail about our thinking about how exactly that integration might occur, but it seems like a very natural and complementary division of labor. But I do want to emphasize, it's not removing any of the privacy and security work from this governance workgroup. It's just gaining some additional input from the tiger team, which has already begun to look at those.

John Lumpkin – Robert Wood Johnson Foundation – SVP & Director
Other thoughts?

Judy Sparrow – Office of the National Coordinator – Executive Director
John, we need to do public comment if anybody from the public cares to make a comment.

John Lumpkin – Robert Wood Johnson Foundation – SVP & Director
Yes. You ruined my surprise.

Judy Sparrow – Office of the National Coordinator – Executive Director
I am so sorry.

John Lumpkin – Robert Wood Johnson Foundation – SVP & Director
If we have gone through our agenda, as all FACA committees who do have the opportunity to see if there are any individuals from the public who have comments about the material that we discussed.

While we're waiting, I wanted to wish everyone a good and safe Labor Day weekend.

Judy Sparrow – Office of the National Coordinator – Executive Director
Thank you. Same to you.

Operator
We have Rachel Donohue on the line.

W
This is the Captioner speaking for Cheri Reynolds. Do you have any health info exchange include consumers or the consumer voice?

John Lumpkin – Robert Wood Johnson Foundation – SVP & Director
I think the answer to that question is similar to the one that Christine Bechtel suggested that we would ask questions when we are having our hearing, so I don't know if there are any on the line who know the specific answer to that question, but that's one of the things that we want to determine.

W
Carol, you may want to speak about your developer challenge that you're doing with Health 2.0.

Carol Diamond – Markle Foundation – Managing Director Healthcare Program
I'd be happy to point everyone to the connecting for health Web site, and there's information there. But I think the question is more about including, making sure to include information exchanges that are both directly involving consumers in terms of making information available to them, and also involving consumers or individuals in their governance processes. And I think that is something we have to create a set of questions around.

John Lumpkin – Robert Wood Johnson Foundation – SVP & Director
Do we have other questions?

Operator
No, we do not have any other ones.

John Lumpkin – Robert Wood Johnson Foundation – SVP & Director
Okay. Well, I'd like to thank everyone then, and thank you … safe and happy holiday.

Public Comment Received During the Meeting

1. The Panel 1 is to address the model used by Visa - e-Consortium Governance Structure

2. Could you send the link to the whitepaper to everyone?
http://www.nationalehealth.org/uploadedFiles/Home/Events/Board_of_Directors_Meetings/July_7,_2009/NHIN%20Governance%20White%20Paper%20-%20FINAL%20062909.pdf